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ABSTRACT

The report summarizes a meeting of the World Health Organization's Working Group on Systems for Provision of Aids for Disabled Persons. The meeting was convened to discuss technical aids and ergonomic measures to bring greater independence to disabled people and the need to systematize services for the disabled in their own environments. Following a brief introduction and a section of background information, the Telemark pilot project of the Technical Aids Centre in Norway is summarized in an outline describing its basic concept and principles, organization of the provision system, daily work at the Centre, and results. An amalgamation of the reports of the various conference subgroups is provided next; this covers: the scope of a technical aid service, organization and administration, the role of the consumer, the role of the rehabilitation engineer, classification and nomenclature, information systems, and general comments. Twelve conclusions and recommendations include the need for development of community-based service provision, a systems approach, improved information exchange, and internationally agreed-upon criteria and protocols for evaluation/testing. (DB)

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# *Systems for providing aids for disabled people*

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ВСЕМИРНАЯ ОРГАНИЗАЦИЯ ЗДРАВООХРАНЕНИЯ
ЕВРОПЕЙСКОЕ РЕГИОНАЛЬНОЕ БЮРО

# SYSTEMS FOR PROVIDING AIDS FOR DISABLED PEOPLE

Report on a WHO meeting

Skien, Norway
25-27 February 1985

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Note

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## 1. Introduction

A Working Group on Systems for Provision of AIDS for Disabled Persons was held at Skien, Norway, and was hosted by the Ministry of Health and Social Welfare, the Directorate of Health, and the Norwegian Council on Technical Aids for Handicapped Persons. The participants are listed in Annex 1. The meeting was chaired by Mr O. Lorentsen and the Rapporteur was Professor J. Hughes.

The meeting was convened in order to discuss technical aids and ergonomic measures that would bring greater independence to disabled people of all ages, and how services have to be made systematic if the problems of users in their own environment are to be solved.

The participants received presentations based on the experience of the Telemark project in Norway and visited the Technical Aids Centre, the philosophy of which is described herein. Participants made presentations describing their national situations in respect of the provision of aids.

Following this, subgroups were formed to discuss the various aspects of provision and technology. The subgroups produced reports which were discussed, moderated and agreed in plenary session. This report represents the amalgamation of these separate reports, and is followed by general conclusions and recommendations, also discussed and agreed in plenary session.

## 2. Background

In most countries, the provision of aids for the disabled is not carried out within the framework of a clearly defined system. This is not surprising as, for the most part, such provision has involved a gradual evolution of a new multidisciplinary activity that does not fit comfortably within existing infrastructures. This leads to the identification of a number of questions, the answers to which must be central to a more effective use of resources.

- Are there fundamental guidelines that may be offered in respect of the system of provision (as opposed to the mere distribution) of aids which, adapted to account for geographical, cultural, economic and other considerations, will provide a basis for rational development in this field?

- The random and relatively uncontrolled development of this activity has led to a proliferation of devices. How can rationalization be achieved through systematic evaluation, so as to quantify actual performance in relation to developers' claims, and comparative performance where alternative solutions may be judged on the basis of economics, marginal benefit, patient choice and other factors?

- While systems of provision may vary from country to country (as may the devices themselves), experience gained should be readily available, both on a national and an international basis. This applies both in respect of the professionals involved and the patient groups. How can an "international language" be developed to facilitate this interchange and how can the dissemination of information be effected?

- Considering national experience, such as the so-called Telemark project referred to later, how can the international community benefit from this local experience?

The answers to these questions will not provide an absolute basis for national solutions. They may, however, provide a background against which planned development may be more effective.

## 3. Definitions

It may be useful for the purposes of this document to examine some of this nomenclature in a conceptual way.

Disability. Each individual possesses a functional capability. The so-called normal individual's functional capability more or less matches the demands of living in the normal environment. Disability applies when there is a deficit between environmental demands and functional capability.

Handicap. Handicap is the hurdle or the deficit between demand and capability.

Technical aid. A technical aid is a device or a technique which is applied either to the environment to reduce the demands or to the individual to increase functional capability. The net effect is to minimize handicap.

## 4. Telemark pilot project (Technical Aids Centre, Norway)

### 4.1 Basic concept and principles of the project

The aim of the Centre is to provide technical aids for all types of handicap. The provision of aids should consider the overall situation of the handicapped individual and solve practical problems in daily life. Technical aids should be available for the total population of Telemark county (population 160 000) regardless of age or location.

### 4.2 Organization of the provision system

The Centre is an administrative autonomous part of the health care system in the county. One of its main tasks is to coordinate the provision of aids in hospitals, in primary health care, and in any other part of the public service system coping with problems of handicapped people. Emphasis on primary health care increases the availability of technical aids.

The Centre provides information, know-how, advice and technical aids to all other parts of the provision system, including the users themselves, and thus bridges and unites the different parts.

The Centre is divided into four sections - vision, hearing, mobility and administration. The 19 employees represent 13 different disciplines - therapeutic, educational, technical and administrative; close collaboration is ensured with the clinical wards at the regional hospital. The Centre has its own building, consisting of offices, laboratories, workshops and storage.

### 4.3 Daily work at the Centre

The provision process includes classification of handicapped persons, assessment, evaluation of alternative aids, instruction, technical services and follow-up of the user to ensure that the solutions are adequate.

The disabled may be referred to the Centre by hospitals, the primary health care system, schools, social workers or employers. The disabled themselves, or their families or friends, may initiate the provision process.

The identification of problems will, in most cases, include evaluation of the environment where the aids are to be used, and the therapists in the Centre therefore perform domiciliary services, combining home visits and cooperation with primary health care personnel in the communities.

In some cases, the Centre refers the user to a hospital or the primary health care system for further diagnosis.

The provision of aids demands the maintenance of a stock. This makes it possible to negotiate prices with commercial suppliers and to recirculate aids no longer in use. Immediate delivery of aids to users is also possible as a consequence.

### 4.4 Results

The Centre was started in 1979, since when the number of aids provided in Telemark has doubled more than four times. Two thirds of this increase is in the provision of aids to those 65 years old or more. In 1983, 60% of aid provision was carried out by the Centre, 20% by hospitals and 20% by the primary health care sector. Nearly 20% of users were given recirculated (refurbished) aids, and negotiation on prices reduced costs by approximately 25% on average.

The usefulness of aids, as reported by the users, is closely linked to the degree of instruction in their use by the providers.

## 5. Report

### 5.1 The scope of a technical aid service

Technical aids are devices provided to protect, correct, compensate or substitute, so as to obtain maximum efficiency and provide maximum independence for disabled people and allow them to take an active part in society.

There are certain sophisticated devices implanted or directly administered by the hospital system, such as life-saving machines, which should not be included in the scope of these recommendations. This presentation concentrates on aids in the field of mobility, vision, hearing, speech and other means of communication, personal hygiene, dressing and other activities of daily living.

The recommendations encompass technical aids and ergonomic measures to reduce handicapping conditions in public and private transport, in housing and public buildings, at school and at work, and in leisure and sport.

The system should:

- be based on proper assessment of individual needs in the context of the family and the community;
- be based on a procedure for providing appropriate aids which will combine the following aspects: usefulness, simplicity (if possible), acceptability, and sufficient control through follow-up examinations;
- develop a supply policy to secure easy access, quick response and economical administration,
- provide comprehensive public information to professional experts involved, to allied personnel in the health and social sectors, and to the disabled themselves and their organizations;
- secure adequate training and education in all parts of the provision process and instruction in the use, maintenance, service and repair of aids;
- be backed by appropriate legislation to ensure that technical aids become an integral part of the rehabilitation process in a comprehensive health and social care system.

5.2 Organization and administration

The need for technical aids should be assessed within the primary health care system, and the provision of technical aids should therefore be integrated at community level. Adequate knowledge of technical aids must be included in the basic education and training of those providing health care and social welfare.

If necessary, the establishment of a technical aids centre in close linkage with the hospital system, as well as schools, employers and social agencies, might be considered. Such a centre should secure technical, therapeutic, educational and administrative skills.

5.3 The role of the consumer

The individual user must participate in the assessment of his or her needs and of the aid provided. Disabled people should be involved in the organization and planning of the services, including the identification of gaps. Organizations of disabled people should also assist in identifying individuals in need.

5.4 The role of the rehabilitation engineer

The participation of bioengineers in the team approach for the provision of technical aids, together with health personnel, social workers and the users themselves, will form a necessary stimulus for development in this field and is therefore highly recommended.

5.5 Classification and nomenclature

A detailed international classification of technical aids is absolutely necessary. The Nordic classification system may serve as a sound basis. The new system should give even more space and flexibility to enable the inclusion of new aspects and development. To review the recommended classification system and to continue to work on further improvement, the Working Group felt that it would be desirable to set an advisory committee.

The Group was aware, however, that any classification could only be general and could not cover the individual needs so important in the rehabilitation process. As translation into different languages might be difficult, terms should be carefully selected and be exactly defined.

To ensure quality, usefulness, practical value and technical excellence, all aids should be evaluated/tested by a special committee at national level, which should include rehabilitation professionals, technicians, appropriate categories of users, etc. If possible, the actual price should be compared with the benefit expected. Uniform criteria and a common protocol should be developed.

5.6 Information system

The great need for and rapid development of technical aids is in striking disproportion to the availability of knowledge. Therefore, an international information system is urgently needed, both for the providers and the users. This would permit distribution of objective information and decrease dependence on information from the producers. For maximum efficiency, the information system should be designed to provide information to the users themselves, the professionals and the producers, as well as policy-makers and decision-makers.

The number of technical aids, their great variety, and the need to select the best aid for the particular individual makes it desirable to establish a computerized data information system. Such a system would not only facilitate the choice of the most appropriate aid but would accelerate distribution and stimulate the development and innovation of further technical aids.

It was recognized that several initiatives were already under way on classification, a multilingual thesaurus, evaluation and information at national and international levels. Since the meeting stimulated great interest and identified needs in all aspects of technical aids, it was recommended that a further meeting on the subject should be organized with two main aims:

- coordination of current initiatives
- involvement of all the European Member States of WHO interested in the coordinated activity.

5.7 General comments

WHO should assume responsibility for identifying needs and collecting information on total assessment procedures as a basis for improving technical aid systems in the Member States.

Nongovernmental organizations in the field should encourage research and development as well as the application of knowledge. They should disseminate information and stimulate the relevant national organizations to apply such information to national needs.

6. Conclusions and recommendations

(1) There is a need to develop community-based provision and to strengthen the integration of primary health care, care of the handicapped, and the assessment and application of technology.

(2) A systems approach to the provision of technical aids will improve effectiveness and efficiency, as identified in more detail above.

(3) It is important to improve the exchange of information on such projects as that in Telemark.

(4) The experience of the Telemark project should be the subject of a cost-benefit analysis with an extrapolation to account for expansion to the total Norwegian provision. Factors should be identified affecting potential application in other national settings.

(5) Other pilot projects should be identified and/or encouraged and subjected to the same analysis.

(6) It is essential to collect, exchange and disseminate information on evaluation/testing programmes.

(7) It is desirable to develop internationally agreed criteria and protocols for evaluation/testing.

(8) It would be desirable to have a uniform system of terminology and classification. It is noted that national and other groups are active in this area; they should be mindful of the need for compatibility.

(9) An international information network based on compatible classification should be established. WHO should play a central role in this, establishing such advisory committees as may be necessary.

(10) Nongovernmental organizations, such as the International Society for Prosthetics and Orthotics, the International Federation for Medical and Biological Engineering, and Rehabilitation International, together with user organizations should be encouraged to assist WHO and, as appropriate, national bodies by playing a consultative and supportive role in this area.

(11) In supporting this report and its conclusions and recommendations, the participants express their willingness to be part of a network to assist WHO in this field.

(12) Recognizing the value of this meeting in stimulating national developments, a follow-up meeting should be organized within the next year.

Annex 1

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ЕВРОПЕЙСКОЕ РЕГИОНАЛЬНОЕ БЮРО

Working Group on Systems for Provision of Aids for Disabled Persons

Skien, Norway, 25-27 February 1985

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SUMMARY REPORT

## Introduction

The meeting was attended by some 20 physicians, health care administrators and bioengineers dealing with the provision of care of disabled persons.

Different types of health care system, economic system and geographical and population characteristics may call for different ways and means of providing aids for disabled persons. There are, however, some common features that ideally should be met:

- proper assessment of individual needs
- usefulness
- simplicity if possible
- acceptability
- follow-up of use
- easy access
- low/no cost to user
- cost-effectiveness for the provider.

These should be heavily supported by:

- comprehensive information to professionals and allied personnel in the health and social sectors;

- comprehensive information to the disabled and their organizations;

- adequate training and education in the provision of aids and in their use, maintenance, service and repair;

- appropriate legislation that guarantees the role of technical aids as an integral part of the rehabilitation process in the health and social care system.

Identification and determination of the need for technical aids is a matter for the primary health care system, and the provision of technical aids should be integrated at the community level. The basic training of health and social care personnel is therefore important. Communities might collaborate in forming technical aids centres, which would provide the necessary technical back-up for primary care and have close connections with hospitals, schools, employers and social agencies.

The individual user must participate in the assessment of his or her needs and of the aid provided. Disabled persons should be involved in the organization and planning of the services, including the identification of shortcomings, and organizations of disabled people should also assist in identifying individuals in need.

The technical aids problem must be solved on a multidisciplinary and international basis, and a detailed classification is therefore mandatory. The Nordic classification may serve as a base for this, but an advisory committee will need to be formed to develop the system.

The quality of aids should be evaluated by multidisciplinary committees at the national level, but uniform criteria and common protocols should be developed.

An international computerized data base should be developed for making the information easily accessible to users, professionals, producers and policy-makers.

WHO should assume responsibility for identifying needs and collecting information on assessment procedures.

Nongovernmental organizations should encourage research and development, disseminate information, and stimulate national organizations to adapt available information to national needs.

Conclusions and recommendations

1. There is a need to develop community-based provision and to strengthen the integration of primary health care, care of the handicapped, and the assessment and application of technology.

2. A systems approach to the provision of technical aids will improve effectiveness and efficiency.

3. It is important to improve the exchange of information on such projects as that in Telemark, Norway.

4. The experience of the Telemark project should be the subject of a cost-benefit analysis, with extrapolation of the results to the whole of Norway. Factors should be identified affecting potential application in other national settings.

5. Other pilot projects should be identified and/or encouraged and subjected to the same analysis.

6. It is essential to collect, exchange and disseminate information on evaluation/testing programmes.

7. It is desirable to develop internationally agreed criteria and protocols for evaluation and testing.

8. It would be desirable to have a uniform system of terminology and classification. It is noted that national and other groups are active in this area, and they should be mindful of the need for compatibility.

9. An international information network based on compatible classification should be established. WHO should play a central role in this, establishing such advisory committees as may be necessary.

10. Nongovernmental organizations, such as the International Organization of Prosthetics and Orthotics and the International Federation for Medical and Biological Engineering, and user organizations should be used by WHO and, as appropriate, by national bodies in a consultative and supportive role in this area.